Organ & Tissue Donation:

A Plan for All Nevadans

Putting Assembly Bill 497 Into Action

Co~Chairs:

Assemblywoman Dawn Gibbons Former Attorney General Frankie Sue Del Papa



Mission Statement

To better educate and inform potential organ and tissue donors about the extraordinary need for organ donation, and how they can give "The Gift of Life." To create a cooperative and proactive coalition among donation organizations, health care professionals and members of the community that will serve to enhance the lives of those in need of organ and tissue donation and their families.



Members of the Organ and Tissue Donation Task Force

Founding Chairs: Former Attorney General Frankie Sue Del Papa

Assemblywoman Dawn Gibbons

Members:

Frankie Sue Del Papa
Assemblywoman Dawn Gibbons
Rhonda Bavaro, Department of Motor Vehicles (Ex-Officio Member)
Lisa Black, Nevada Nurses Association
Stephanie DeBoor, Washoe Medical Center
Elisa Giglio-Siudzinski, Saint Mary's Regional Medical Center
Larry Matheis, Nevada State Medical Association
Michael Pennington, Reno-Sparks Chamber of Commerce
Debbie Pinjuv, The Transplant Network
Ken Richardson, Nevada Donor Network
Anne Sagel, Nevada Donor Network
Cassandra Smith, Sierra Eye & Tissue Donor Network
Claudia Swift, Sunrise Hospital Medical Center
Fina Wardle, University Medical Center

Friends of Task Force:

Attorney General Brian Sandoval Senator Raymond Rawson

Senator Valerie Wiener Assemblyman John Oceguera Maureen Brower, Governor Guinn's Office~LV Christie Callon, Northern Nevada Medical Center Jennifer Carvalho, Attorney General's Office Danita Cohen, KOLO-TV Antonia Cowen, Office of the Attorney General Carol Falk, DMV Steve George, Secretary of State's Office Mylan Hawkins, Nevada Diabetes Association Timothy Hay, Consumer Advocate Caryn Key, UNLV Office of Research & Graduate Studies Jack Kim, Sierra Health Services Erik Lauritzen, Artist and Kidney Transplant Candidate Keith Macdonald, Nevada State Pharmacy Board Woody Marshall, Intermountain Donor Services Deena McKenzie, Carson-Tahoe Hospital Alice McKinney, Donor Quilt Mitch Nowicki, REMSA Peggy Pound, AMEC Virginia Reese, California Transplant Donor Network Heidi Smith, Liver Transplant Candidate Rev. Richard Smith, St. Rose Dominican Hospital Marie Soldo, Sierra Health Network Noel Tiano, Nevada Center for Ethics and Health Policy Bill Welch, Nevada Hospital Association Judy Wright, Nevada State Health Division Cynthia Wyett, Washoe County District Attorney's Office

Administrative Support for Task Force:

Danelle Snodgrass, Attorney General's Office - Bureau of Consumer Protection John Michela, Deputy Attorney General, DMV – Legal Advisor to Task Force Marilyn Skibinski, Attorney General's Office - Bureau of Consumer Protection

(last update: November, 2004)

Protocols

The Chairs are responsible for: serving as spokespersons for the Task Force; organizing Task Force meetings; implementing the goals, vision, and mission statements of the Members of the Task Force; coordinating various outreach programs with affected parties; providing recommendations to the Legislature; appointing members to serve as Members or Friends of the Task Force, including subcommittees and ad hoc committees; and are voting members of the Task Force.

Members of the Task Force are appointed by and shall serve at the pleasure of the Chairs to implement any and all necessary actions and programs outlined in the Task Force Action Plan. The Members of the Task Force are comprised of representatives from various health care organizations and from the public. The Members will assist in fulfilling the goals, vision and mission statement of the Task Force. The Members are voting members of the Task Force. When a Member cannot attend a Task Force meeting they should appoint a proxy to attend on their behalf and that proxy should be thoroughly briefed on the issues and matters that will be discussed and voted on at that meeting.

The Friends of the Task Force are appointed by and shall serve at the pleasure of the Chairs. The Friends of the Task Force represent various health organizations and constituency groups that provide recommendations to the Members for consideration regarding the direction of the goals, vision and mission of the Task Force. The Friends of the Task Force are non-voting members of the Task Force.

The Appointment of Prospective Tissue Bank Members to the Task Force: In order to qualify for membership on the Nevada Organ & Tissue Donation Task Force, any organ procurement organization or tissue bank not already represented on the Task Force must:

- 1) Be EBAA, FDA or AATB accredited and/or registered;
- 2) Have a Nevada business license;
- 3) Have an agreement concerning organ or tissue procurement with a Nevada hospital; and
- 4) Be a non-profit entity.

Upon meeting these qualifications, an organ procurement organization or tissue bank shall not become a member unless it is appointed by the Chairs. These qualifications do not apply to prospective members that are not organ procurement organizations or tissue banks.

Administrative Staff members assist in implementing Task Force meetings and all necessary requirements to further the goals, mission and vision of the Task Force. Administrative Staff are non-voting members of the Task Force.

The Task Force shall meet on a quarterly basis unless important matters come up that require the attention of the Task Force.

Approval of Expenses for the Task Force: Expenditures for the Task Force over \$1,000 must be approved by the Task Force Members at the quarterly meetings. In between meetings if an opportunity presents itself and the expenditure is under

\$1,000, approval can be obtained by either of the Chairs <u>and</u> Ken Richardson from the South. Routine ordering of brochures, pins, and other educational materials can be done by the administrative staff without prior approval of the Task Force Members.

RESOURCE ORGANIZATIONS

Coalition on Donation 700 N. 4th Street Richmond, VA 23219 (804) 782-4920 www.donatelife.net United Network for Organ Sharing POB 13770 Richmond, VA 23225-8770 (804) 330-8503 www.unos.org

Sierra Eye & Tissue Donor Services 1130 Ryland Street Reno, NV 89502 (775) 323-1566 www.dcids.org UMC Transplant Services 1800 W. Charleston Las Vegas, NV 89102 (702) 383-2224 www.umc-cares.org

The Assn. of Organ Procurement Organization 1364 Beverly Rd., Ste 100 McLean, VA 22101 (703) 556-4242 www.aopo.org

Washoe Medical Center 75 Pringle Way Reno, NV 89502 (775) 982-4511 www.washoehealth.com

The Transplant Network 1130 Ryland Reno, NV 89502 (775) 324-4501 www.thetransplantnetwork.com

California Transplant Donor Network 1611 Telegraph Ave., Ste. 600 Oakland, CA 94612 1-800-553-6667 www.ctds.org

Nevada Donor Network, Inc. 2085 E. Sahara Ave. Las Vegas, NV 89104 (702) 796-9600 www.nvdonor.org Sunrise Hospital & Medical Center 3186 Maryland Parkway Las Vegas, NV 89109 (702) 731-8659 www.sunrise.com

INTRODUCTION

In recent years, the United States has experienced a tremendous increase in the demand for organ and tissue donations. While the need for organ and tissue donations has grown astronomically, the number of donors has not. The shortage of donations has reached unprecedented levels. According to UNOS (United Network for Organ Sharing), more than 90,000 people nationally are currently waiting for an organ or tissue transplant; every 14 minutes a new name will be added to the list; and every day 12 people die in the United States because they failed to receive a transplant in time.

One donor can help the lives of 100 people through organ and tissue donations, i.e.; heart, kidney, lung, pancreas, middle ear, cornea, small intestines, tendons, cartilage, eyes, bones and bone marrow. Some of these donations can be made by the living, while others can obviously only be made by someone who has passed away.

Now, more than ever, it is imperative that we as Nevadans and as a society recognize the importance of organ and tissue donation. The Task Force seeks to encourage all Nevadans to pledge the gift of life by becoming an organ and tissue donor.

During the 2001 Legislative session, the Attorney General, Frankie Sue Del Papa, testified in support of Assembly Bill 497, which was sponsored by Assemblywoman Dawn Gibbons and Senator Ray Rawson and several of their colleagues. Assembly Bill 497 requires the Department of Motor Vehicles to work in conjunction with the Attorney General's Bureau of Consumer Protection to create and maintain an accurate list of individuals who have pledged to be organ donors.

This will allow candidates to receive their transplants in a shorter amount of time, ease the burden of family members, and provide support to transplant services.

The Task Force hopes to accomplish the following goals:

- To commence an aggressive, proactive campaign to educate and inform the public about the need for organ and tissue donation
- To work with a contracted organization and the Nevada DMV Offices to maintain the state organ donor registry
- To implement a donor education program for Nevada schools, especially in driver's education classes
- To partner with the Nevada DMV Offices throughout the state to display reader boards, posters and other methods to promote organ donor awareness
- To promote the Nevada organ donor license plates
- To increase the awareness of health care professionals about the critical role they play in the organ donation process
- To promote collaboration and communication among local organizations, thereby creating a solid foundation of grass-roots support for organ donation
- To work with federal, state and local government agencies and other interested parties to form and implement policy initiatives that will assist in meeting these goals

To accomplish these goals, we must first begin by better educating the public about the tremendous need for organ and tissue donation. The Task Force will work in conjunction with various media outlets to help accomplish this goal. Public

Service Announcements can be an invaluable tool in this process, as well as brochures, media presentations and news releases.

The Task Force will also focus on better educating health care professionals about the critical role they play in organ and tissue donation. It is essential that health professionals who provide support or primary care to critically injured individuals and others become an important player in the process of providing information to family members about the benefits of organ and tissue donation.

The Task Force must also work to strengthen grass roots efforts through partnerships with the Nevada League of Cities, Nevada Association of Counties and additional organizations that can assist in educating the public at the local level, as well as with helping to distribute information to Nevada's rural communities.

TASK FORCE ACCOMPLISHMENTS

- Confirmed anchor organization for the Task Force
- Drafted a mission statement
- Conducted initial Task Force planning meeting in the North and South
- Solicited co-sponsoring organizations
- Drafted an Action Plan
- Created a brochure for dissemination at DMV and distribution to public
- Ordered Spanish version of organ donor brochure, personalized with task force contact information
- Ordered African-American version of organ donor brochure, personalized with task force contact information

- Created a multi-use, generic article that can be sent to various organizations throughout the state.
- Reached a tentative contract agreement with the Nevada Broadcasters Association for the taping and airing of a specially designed Public Service Announcements in regards to organ and tissue donation.
- Developed DMV donor awareness educational series for employees
- DMV has all procedures in place to implement AB 497
- DMV has established protocols and procedures to work with a contracted donor registry.
- DMV has established protocols with the Attorney General's Bureau of Consumer Protection regarding transfer of funds
- Organ Donor license plate has been created and is available to the public
- Information on organ donation has been disseminated to many healthrelated boards and commissions and other members of the health community and ongoing efforts will continue
- Speaker's Bureau Training Manual has been created and printed for distribution to service organizations, attorneys, churches and others who want to be involved in this educational program
- The Task Force has developed a budget to accomplish our goals efficiently and effectively for funding the printing of brochures and other educational materials.
- The Task Force conducted a Special Summit on Organ Donor Registry Issues to discuss the future of the organ donation registry system for Nevada.
- The Nevada DMV and the Task Force are working together on a project that sends out flyers, created by the Task Force containing information about organ and tissue donation and the organ donor license plates, which

accompanies the vehicle registration renewal notices that are sent out to thousands of Nevadans every month.

SHORT RANGE GOALS

- Continue to work with a contracted organization and the Nevada DMV to maintain the donor registry.
- Continue our concerted effort to inform all health-related boards and commissions and other members of the health community.
- Continue to acquire statistics from DMV (ex. age categories, location of people agreeing to be donors), organ procurement agencies (ex. number of donors per month) and UNOS (ex. number of transplant candidates waiting for organs in Las Vegas, Reno, etc.). These statistics will help the task force monitor our successes and weaknesses throughout the state.

LONG RANGE GOALS

- Commitment to enhance medical education throughout the state in regards to organ and tissue donation.
- Work toward re-establishing heart and liver transplant centers in Nevada.
- Improve Medicaid program/funding for transplant surgeries.
- Establish priorities for future legislative action.

MEDIA/PUBLIC OUTREACH

• Organ and Tissue Donation Action Plan (Spanish version, too) will be continually updated, with latest version available to media.

- Brochures (English, Spanish and African American) have been developed and are currently in use by DMV, health fairs, used at speaking engagements, and through partner organizations to spread the word.
- Generic article highlighting AB 497 and organ donation has been sent to various groups, organizations and media outlets.
- Editorial article has been sent to all newspaper outlets.
- PBS television stations have been contacted in the north and south to develop possible programming relating to organ and tissue donation.
- Hispanic media and organizations have been enlisted for their support.
- Various radio stations with talk shows have been contacted for various organ donor events.
- Nevada Broadcaster's Association and Mark One Productions, Inc., have been contacted regarding the making and airing of Public Service Announcements across the state.
- Cox Cable in Las Vegas and AT&T in Reno have been contacted regarding taping and airing of Public Service Announcements.
- Website for Task Force has been set up with appropriate links to other local and national groups.

SPEAKERS BUREAU

Debbie Pinjuv of The Transplant Network has agreed to take on the responsibilities of creating and maintaining a Speakers Bureau. One of the main focuses of the Speakers Bureau will be keeping the Department of Motor Vehicle office clerks educated throughout Nevada about the process of organ and tissue donation. Information about AB 497 and how it affects DMV is also part of this training. The brochures the task force has developed will be available at each of the DMV offices.

Members of the Speakers Bureau will also address various groups, including schools, service organizations, businesses, etc., to help educate the community about organ donation.

LEGISLATIVE COMPONENT

Assemblywoman Gibbons and Senator Ray Rawson will be working with the Nevada State Legislature on bills that will enhance provisions of AB 497 as well as any new bills that will affect organ and tissue donation in Nevada. Assemblywoman Gibbons has also recruited additional state legislators who have agreed to help carry the torch during future legislative sessions.

Deputy Attorney General John Michela, legal advisor to the Task Force will work with the legislators in drafting the appropriate language for any bill draft requests.

The Task Force will seek recommendations from members and others regarding said language.

IMPORTANT DATES

- February 14 of each year: National Donor Day
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- April: National Organ & Tissue Donation Awareness Month
- July & August designated days are different each year: <u>U.S. Transplant</u>
 Games
- August designated day is different each year: National Minority Donor Awareness Day (August 1, 2004)
- *November* designated days are different each year: <u>National Donor Sabbath</u> (November 12-14, 2004)

• *November* - Thanksgiving Day of each year: <u>National Give Thanks, Give Life</u>
<u>Day</u> (November 25, 2004)

<u>media</u>

Media inquiries can be directed to the following members of the Task Force:

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